

Developmental Disabilities Council  
Reading Cover Page

Date: November 18, 2004

Meeting: Community Supports/Housing Workgroup

Reading Number: 04-C-11

**Issue:** Core Indicators Report

Included in this reading:

Core Indicators Report on Family Supports Services.

Background/Summary:

This is the second report issued by the Council based on the data from the Core Indicators survey. The data collected in this round is about family support services. The report contains key recommendations for system change based on these data.

Action: Presentation and Discussion



# **Washington State Children's Core Indicators Review Panel Results**

**Washington State Developmental Disabilities Council  
October 2004**

# Introduction

The Developmental Disabilities Council convened a panel comprised of self-advocates and family members to review the results of the Children's Core Indicators surveys done in Washington State in 2000 and 2002. The Core Indicators is a national study that assesses performance and outcome indicators for participating state developmental disabilities service systems.

The Washington State Core Indicators survey participants were selected from the caseload of the Division of Developmental Disabilities. Families were asked about the services they and their children received through the Division.

Reviewing Washington State and national data from 2000 and 2002, the panel worked to develop systems change recommendations to the Developmental Disabilities Council and the Division of Developmental Disabilities. The panel met two times in July 2004 and provided follow-up feedback in August 2004.

After close examination of the data from the survey, the group identified recommendations for improvements in four areas. These areas were:

- Services & supports/access
- Information and planning
- Choice and control
- Community connections

Under each identified area, the recommendations are in rank-order, with the highest-ranking recommendations listed first. The number following each bulleted item is the composite score the item was given by the review panel. Ranking for each bulleted item is from one to five, with five being the highest recommendation.

Each area includes a narrative with comments about the supporting data and other input from the committee members. The statistics quoted in the following pages are from the Core Indicators 2002 data.

More detailed information about the Core Indicators Surveys and the panel members is also listed in Appendix A.

## What is the Core Indicators Study?

*The National Core Indicators is a collaboration among participating National Association of State Developmental Disability Directors (NASDDs) member state agencies and Human Services Research Institute (HSRI), with the goal of developing a systematic approach to performance and outcome measurement.*

*Through the collaboration, participating states pool their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out comparable data collection strategies, and share results.*

*This multi-state collaborative effort to improve performance is unprecedented.*

*-[www.hsri.org/nci/](http://www.hsri.org/nci/)*

## Services & Supports/Access

Washington State families had the lowest number of families reporting they received the services and supports they needed out of seven states completing the surveys. Only 36.7% of families indicated that services and supports usually or always met their family's need. Only 35.6% indicated supports were always or usually available when they needed them; significantly below the national average of 46.4%. In Washington, the three services families reported using most were specialized services, out-of-home respite care and in home support, respectively.

In an emergency or crisis situation, families indicated that they were always or usually helped 35.4% of the time, compared to the national average of 52.4%.

Families said there is a lack of access to support workers who can communicate with their children who do not speak English, or use a different way to communicate. Only 17.6% of families indicated support workers with these skills/attributes were always or usually available.

Access to special equipment is also a concern for families. Only 44.6% of families indicated their children had access to the special equipment or accommodations their children needed.

*"Families shouldn't have to resort to moving their children out of their home to get services. When families don't get the support they need, especially emergency support, they feel like that is their only option."*

*-Review Panel Member*

## Recommendations

**We recommend the Division request increased funding, and increase the availability and options for in-home respite care and family support.**

- Increase/fund in-home respite care. (5.0)
- Increase funding and resources for family support. (4.66)
- Provide easier access to resources including respite workers and easier ways to find them. (4.5)

**We recommend the Division improve and increase emergency supports for families and provide earlier intervention to prevent "high stress crises" and preserve families.**

- Improve/increase emergency service supports. (5.0)
- Provide earlier intervention to prevent "high stress crises" and maintain families. (4.3)
- Prioritize higher risk/need and provide with appropriate level of service. (4.3)
- Case managers should ask if families' needs have changed. (3.16)

**We recommend increasing the provision of services in the language which families and their children speak.**

- Increase or establish non-English speaking/alternative communication resources. (4.16)

## Information and Planning

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Compared to other states participating in the survey, Washington State ranked the lowest in information and planning. 29.9% of families stated they always or usually receive information about the services and supports that are available to their children compared to the national average of 45.1%. Only 48.5% of those families in Washington who received information stated that the information was always or usually easy to understand.

33.3% of Washington families reported they usually or always receive information about the status of their children's development versus 49.0% for the national average. When families do receive this information, only 52.1% report the information is always or usually easy to understand versus a 62.1% national average.

Families are highly dependent on case managers for information. Case managers were the most-mentioned resource for information about public benefits and community support services and assistance in accessing natural supports.

Only 32.4% of Washington families stated they get enough information to help them participate in planning services for their children with developmental disabilities. This number was the lowest of all states surveyed.

## Recommendations

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**We recommend increasing the ways families can access information about services provided by DDD and in the community.**

- Provide alternative ways to access the system and increase cultural competency through use of guides, consultants and personal coaches. (5.0)
- Increase information about community connections resources. (4.3)
- Provide e-mail/newsletters for families about specific disabilities, ie. autism, epilepsy. (3.8)

**We recommend the Division provide education and support opportunities in a manner that is easy-to access & understand.**

- Provide educational classes/opportunities to network and information on how to get to services. (4.16)

*"Provide families alternative ways to access the system.*

*Now, families are dependent on their case manager.*

*Families should have other avenues open to them so they can learn firsthand about possible services and ways they can better help their children."*

*-Review Panel Member*

## Choice and Control

Washington State compared favorably with other states in choice and control. High numbers of families stated that they were able to choose the agencies or providers who work with their families. Washington's choice and control over support workers were among the highest of states surveyed, with 54.7% of families stating that they always or usually have control over the hiring and management of their support workers.

Only 13.5% of families expressed that they did not want to have control over the hiring and management of their workers.



Washington families were more likely than other states to know how much money was being spent on behalf of their children. 31.1% always or usually knew how much was spent versus 24.6% for the national average. However, the number is still very low.

Less than half of families stated that someone helps them find community support services.

*"The current system creates a hoarding mentality.*

*Families are afraid to reduce any level of supports they receive because of the fear they will never get them back when they need them again."*

*-Review Panel Member*

## Recommendations

**We recommend the Division continue to provide and increase opportunities for families to exercise choice and control over the services and supports they need.**

**The Division should structure provision of services/supports in a way that moves families towards independence.**

- Services should lead to independence and not create dependency. (5.0)
- Provide support/education to help parents/families/caregivers to move toward independence. (5.0)

**We recommend the Division increase families' awareness of information about resources and services available in the community.**

- Increase information about community connections/resources. (4.3)

## Community Connections

According to the survey data, families in Washington are having difficulty getting providers to help them plan or provide support to use the generic services available in their community (e.g. through recreation departments or churches). Only 19.6% of families surveyed stated providers always or usually help them do this. This number was the lowest among the states surveyed.

Generally, families didn't feel that their children had **access** to community activities. Only 27.2% of families indicated that their children always or usually had access to community activities. 31.2% of families indicated that their children seldom or never had access to community activities. During the panel review, families said the major barrier for them is transporting their children. Increasing families' access to transportation would improve the quality of life for their children.

Children's ability to **participate** in community activities was also low in the study. 41.4% of families stated that their children seldom or never participate in community activities. Only 47.6% of families reported their children always or usually spend time with children without developmental disabilities.

### Recommendations

**We recommend the Division continue to recognize the value of community inclusion in the lives of persons with developmental disabilities and their families and work with families to increase their ability to be active participants in their communities.**

- Increase information about community connections/resources. (4.3)
- Focus on inclusion of people with developmental disabilities in the community, regardless of the level of disability. (3.8)

**We recommend the Division increase access to assistive technology that will improve children's lives in their home and increase their ability to participate in their community.**

- Increase availability and access to assistive technology (4.3)
- Increase ability to transport people and the provision of support people to assist. (4.0)

*"The number of children who are participating in activities with children not having developmental disabilities actually decreased in the last two years.*

*We need to focus on the inclusion of people with developmental disabilities in the community, regardless of the level of their disability."*

*-Review Panel Member*

## Appendix A: Reviewed Material

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Child Family Survey: Final Report January 2003 (2001-2002 data)  
[http://www.hsri.org/docs/786\\_P4\\_CFS2002final.pdf](http://www.hsri.org/docs/786_P4_CFS2002final.pdf)

Child Family Survey: Summary Report 2000.  
<http://www.ddc.wa.gov/2001%20Core%20Indicators%20Survey.pdf>

## Participating States: 2000 Survey

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Arizona	Utah
Minnesota	Washington
North Carolina	

## Participating States/County: 2002 Survey

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Arizona	Washington
Massachusetts	Wyoming
South Carolina	Orange County Regional Center (CA)
South Dakota	

## Criteria Used to Rank Recommendations

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When evaluating the priority of recommendations the following guidelines were followed:

- Likelihood that the change could occur
- Practical/realistic
- Cost of implementing recommendation is realistic and cost-effective
- Supports stability of family and maintaining the family unit
- Respects diversity
- Values people
- Promotes self-determination
- Foster more independence and productivity
- Moves toward integration into the larger community

## Panel Members

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William Fale	Seattle, Washington
Alison Hahnel	Lynden, Washington
Meredith Moyer	Lynden Washington
Julie Perales	Olympia, Washington
Carolyn Wright	Spokane, Washington